

By Way of Introduction

The new clinical commissioning structures needs patient input at every level if it is to succeed. The patient participation groups (PPGs) which exist in many practices can make an important contribution to this but how can you ensure that they are able to contribute to this process above the level of the individual practice? If you are trying to make patient engagement work for a clinical commissioning group then this paper, which draws on recent work in Lambeth, may help.

PATIENTS UNITED – HEARD AND VALUED

A Great Opportunity

The new integrated local commissioning structure - heralded by the Better Care Fund - challenges CCGs (clinical commissioning groups) and Local Authorities to pool resources to achieve better coordinated health and social care services. To do this effectively, local commissioners need patient and carer in-puts. This is a great opportunity for the patient participation groups (PPGs) set up in many GP practices to contribute to that process and influence services not just in their own surgery, but for all patients in that CCG and Local Authority area.

How to Do That? – the MAC response

How do you build a structure to make the most of the patient contribution to local health and social care provision?

Stocktake

Find out how many GP practices have set up patient liaison or participation groups. Ask questions that will help you decide how active these groups are – not just about frequency of meetings and size of membership. Another sign of life is being able to point to success – defined as changing something so that it makes things better for patients and, at best, the practice as well. Look for evidence of independence – is it a patient who chairs the meetings and do the patients have a say in what appears on the agenda?

Lambeth Healthwatch have recently made available a Mapping Survey of 38 Patient Groups which shows the variety of practice and achievement of those working to engage patients – both practice members and patients¹. An interesting finding for our purposes here is how few had developed systematic contact with other groups in their localities. 14 had such links – 20 did not.

¹ Full details of the survey results for all the individual practices can be found in the Directory of Patient Participation Groups in Lambeth, available from Healthwatch Lambeth.

An accurate understanding of the vitality and current reach of the groups is essential before considering how to make them more effective as a voice in the local health market. If the groups are not flourishing in their home environment – the practice - they will not be able to consider taking on any more ambitious and externally facing role involving other players.

Building on the basics

Once you have an active and interested group of patients with an interest in health and social care, keen to see if they can change things for the better at practice level and beyond and a Clinical Commissioning Group who wants to hear from patients, the two critical elements are in place. Add to that, a Local Authority who wants to make its social care services more user sensitive and better value. Is there a mechanism that can be put in place to bring these elements together in a way that does not crush the life out of the patient voice, stifled by the big boys' bureaucracy?

First - Define the Job

We can all agree I think that the job of the patient participation group is to communicate and influence – this is the business it is in once it has agreed to try and change the wider world beyond the parish pump interests and concerns of its own GP practice – a vital job but not the be all and end all. The next question is the nature of the beast - the organisations and persons - being communicated with and influenced. The patient groups are scattered and isolated and reliant on GPs or others representing their views to the Commissioners. This has to be unsatisfactory and therefore we need a way of consolidating the views of the many into a solid case that convinces the few – the decision makers. This calls for a body to harvest and bind the PPG views into the bales of wisdom – processed into the Weetabix breakfast that will nourish and feed decisions with the patient interest in mind.

An intervening body

The target body – for our purposes here we will assume that body to be the CCG – will be looking for a cost-effective way of building its own listening capacity which will range beyond the views of GP Patient Groups. It would therefore be grateful and be more likely to support with funds a body or process that pulled together the views of those groups and represent them in an accurate and timely way to the decision makers.

One way to do this is to set up a Patient Participation Group Network which would exist to stimulate, gather and then represent the views of the members of Patient Participation Groups in GP practices to decision makers in the area of health and social care taking advantage of the structures and processes established in the local authority area to facilitate patient and community engagement.

Independent and Fearless

The Network's values and vision will be founded on its independence and commitment to reducing health inequalities. It will be fearless in making its opinion known while ready to work with others in the community to achieve its goals. It will seek the views of all in its community and will develop the competencies necessary to gather those views, collate and reproduce them in the way that will maximise the chances of achieving the services that users of health and social care services need and want. It will be transparent in all its work and be accountable to the members of the practice groups whose views it represents. The Network is created from and for practice participation groups. In working collaboratively with the groups, it will reflect the commitments of those groups on diversity, equality and inclusivity.

Hunting and Gathering the Patient View

The functions supporting this role is to help groups define the issues of the day, gather opinions, analyse this data and be an advocate of the views that emerge to decision makers. In order for the groups themselves to be effective players in this process, the Network will develop the capacity of those local practice groups by – for example – securing the delivery of a patient leadership training programme through the practices. To get the point of view over and to reflect that ethos, we recommend the MAC "Up-Across-Over" model of working.

- "Up" means "up from the practices" which are and will remain the main well of LPPGN's strength because members will be patient participation activists and will take intelligence and development opportunities away from and back into their practices in a "conduit fashion" .
- "Across" means "across the practices in each locality" in alignment with the work of the principal health networks.
- "Over" means spanning the whole of the administrative area where the LPPGN is an equal partner with the CCG and the Borough Council and 3rd sector bodies in health and social care decision making.

Support from your local Healthwatch

This will be very useful at all stages in the process but particularly the early stages of the creation of the Network – formless, homeless, fundless - with just a few like-minded people trying to put something worthwhile together. At this stage, a sympathetic Healthwatch can offer help – just offering a room to meet for nothing is a great help. Healthwatch will not generally be in a position to offer funding but the chances are it will have people who understand what patient participation means and how to get such organisations off the ground. Healthwatch depends on having functioning and interested groups of patients to work together on issues. They will be glad if a Network or similar saves Healthwatch the time and effort of approaching all local GP Patient groups. There may well be demarcation issues to be sorted out but the argument for co-operation will be compelling we believe for

a Healthwatch trying to make the most of its limited resources. A Network along the lines we suggest is an ally not a competitor.

Support from the CCG

In return for this essential contribution, the CCG will support the PPG Network to strengthen their leadership and ability to influence quality and service development within practices and across the localities. As members of the Primary Care Locality Networks, the PPG Network representatives will input into the locality action plan that underpins implementation of local initiatives such as the Community Based Care Strategy.

Expand the Resource

There is always a risk that such a Network will consist of a very small number of informed, well-connected and active individuals. The cry may be raised that they are 'just the usual suspects'. This sort of accusation can devalue those individuals' contribution. We have lived long enough in the user participation world to know that without these 'usual suspects' the whole apparatus would collapse. The committed and effective volunteer who stays for the long haul is vital but they would be the first to agree that more people from the constituent practices need to be made aware of the opportunity the Network provides. Once identified they need to be skilled up and supported as well as becoming more effective in doing the ground work that they are doing in their own PPG. We believe this is a function of what is generally called "patient leadership". Elections and the adoption of a suitable corporate form such as will be essential.

The Network Takes Shape

It will avoid a lot of discussion and make the Network able to bid for and accept funding, if such groups take the route of forming a minimalist legal entity, a company limited by guarantee (CLG) to be called the (name your Borough) Patient Participation Groups Network Ltd. and known for everyday purposes as the PPGN or the PPG Network

This structure would be robust enough in its governance (but not onerous) to form partnerships and collaborations with stakeholders in the statutory and third-sector worlds, but flexible enough in its application to allow the PPGN to respond to opportunities and challenges and to support its members in their individual work. A CLG is sustainable with minimal governance input and flexible enough to adapt to the needs of emerging PPGs and the developing localities across the borough.

For those who want to understand more about how Patient Participation or Liaison groups function, take a look at a report we wrote a while ago now but still relevant in terms of issues addressed and processes that work.

<http://www.mooreadamsoncraig.co.uk/wp/wp-content/uploads/2009/11/REPORT-AS-SENT-TO-DOH-310308.pdf>